Withdrawing and Withholding Medical Care
an
Oncologist’s View
with an Ob-Gyn Twist

Jed Delmore, MD, FACOG, FACS
Professor of Obstetrics and Gynecology
Division of Gynecologic Oncology
University of Kansas School of Medicine, Wichita
Disclosure/Conflict of Interest

I am constantly conflicted, but, have nothing to disclose
“As a Scottish-Canadian-Californian, I have always said that I have a unique perspective on health care and all things to do with health care, including death and dying: The Scots see death as imminent. Canadians see death as inevitable. And Californians see death as optional.”

Ian Morrison, PhD
Author, Consultant and Futurist.
Outline for Presentation

• Ethical principles of patient care
• Sample cases
• Developing a Plan of Care
• Describing the Potential Risks and Benefits
• The Decision to Start Therapy
• The Decision to Stop Therapy
• Revisit the sample cases and discuss.
History of Human Subjects Protection

- Nuremberg Code (1947)
- Unethical Research in the U.S.
- Declaration of Helsinki (1964)
  - Revised - ’75,’83,’89,’96,’00,’02,’04,’08
- National Research Act (1974)
  - Resulted in The Belmont Report
- Regulations
- Modern Day Problems
During the Nuremberg War Crimes Trials:

- 23 German doctors were charged with crimes against humanity for "performing medical experiments upon concentration camp inmates and other living human subjects, without their consent, in the course of which experiments the defendants committed the murders, brutalities, cruelties, tortures, atrocities, and other inhuman acts."
As part of the verdict, the Court enumerated some rules for "Permissible Medical Experiments", now known as the “Nuremberg Code”. These rules include:

- voluntary consent
- experiment yielded results for good of society
- benefits outweigh risks
- ability of the subject to terminate participation
National Research Act (1974)

• Established the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (i.e., “The National Commission”)

• Initially met over a four-day period in 1976
• Met at the Smithsonian Institute's Belmont Conference Center (thus “The Belmont Report”)
• Monthly deliberations over the next four years
• Resulted in The Belmont Report
Respect for Persons
- informed consent,
- respect for privacy

Beneficence (nonmalficence)
- first do no harm,
- good research design,
- competent investigators,
- favorable risk/benefit analysis:
  - maximize benefits,
  - minimize risks.

Justice
- equitable selection of subjects
- appropriate inclusion and exclusion criteria.
Ethical Principles of Patient Care

• Autonomy
• Beneficence/Non-maleficence
• Justice
Autonomy

• The right to be self-ordering
• Informed Consent
  • Well informed with accurate information
  • Pros and Cons, Risks/Burden vs. Benefits
• Capacity to decide
• Right to delegate decision making
• Right to authorize or refuse treatment
Beneficence / Non-maleficence

• Promote the patient’s best interest
• Minimize harm
  • Primum non nocere = “first, do no harm”
  • Realistically, it should be “do the least amount of harm”
• This is the most difficult to apply in daily practice
Justice

• Treat all patients equally
• Treatment should not be based on race, ethnicity or socioeconomic status.

“Come on over sometime and talk about how all men are created equal, Only some they mo' equal than others.”

Special Care, Buffalo Springfield, 1968. Modified from “Animal Farm”
Case Presentations
Case # 1

- 56 year old woman diagnosed with Stage IIIC ovarian cancer two years ago. Treated with aggressive surgery followed by intraperitoneal chemotherapy. Found to have recurrent cancer six months after chemotherapy and subsequently treated with three different second-line therapies. Admitted now with nausea and vomiting and a high grade small bowel obstruction.
Case # 1 –Gyn Example

• 30 year old Egyptian G2P2 with a history of infibulation as a girl. After moving to New York she underwent deinfibulation for childbirth. Her second delivery was nine months ago. Her husband is an Engineer and she is a Masters prepared Social Worker. They were recently transferred to Kansas by his company. She requests reinfibulation, and if you will not perform it, she will have it done by a non-professional.
Case # 2

• 58 year old female diagnosed with ovarian cancer five years ago. Treatments over time included surgery (multiple), chemotherapy (multiple) and radiation. Her husband is being treated for cancer, the patient is the only source of income, they have declared bankruptcy and live in her daughter’s basement. She now has diffuse metastatic disease and she and the family are pushing for further treatment.
Case # 2  OB Example

• 19 year old G1P0 with ruptured membranes at 20 weeks gestation. She is a college sophomore, living with her grandmother. She got pregnant following a fraternity party and first episode of sexual intercourse. She is seeing you as her grandmother is your patient and respects your expertise
Case # 3

• 46 year old originally diagnosed with Stage IIB cervical cancer with initial treatment involving chemotherapy and radiation therapy. Found to have recurrent cancer involving multiple sites and obstructing her kidneys and colon. Second line chemotherapy failed. She was seen in Consultation at a Cancer Center in Tulsa and underwent two, unsuccessful operations. She was dismissed on chemotherapy, TPN, with bilateral nephrostomy tubes.

• Returns to Wichita and wishes to continue on all therapy locally, but directed by CTCA.
Case # 4

• 66 year old female diagnosed with advanced uterine cancer following surgery. She is mentally handicapped and functions at the level of a six year old. Lives with, and is cared for by her 74 year old sister. The usual post-operative therapy is pelvic radiation followed by 4-6 cycles of chemotherapy. Her sister is the legal guardian and is conflicted as to what to do.
Case # 5

• 79 year old non-English speaking Middle-Eastern female seen in Consultation for menopausal bleeding and found to have Stage III cervical cancer. She lives with, and is accompanied by her son and daughter in law. I explained the diagnosis and the usual treatment to be pelvic radiation. The family refused the use of a professional interpreter and refused to allow the patient to know the diagnosis. Their demand was to tell her she had an infection and the radiation treatments were to treat it.
Developing a Plan of Care

• Accurately describe/discuss the Stage or extent of disease
• What is the outcome without treatment
• Intent of treatment?
  • Cure
  • Live longer
  • Relieve symptoms
• How much toxicity is acceptable?
• Commitment to Treatment Plan
  • Patient = compliance
  • Family
    • Physical, emotional/spiritual, financial
• Revisit the Plan frequently (each visit)
Risks vs. Benefits

• Benefits
  • Cure, feel better, live longer, live better

• Risk of treatment vs. risk of the disease

• Types of Risk/Toxicity
  • Physical Risk
  • Emotional Risk
    • Inability to care for others
    • Inability to care for self
    • Inability to work
    • Burden on family
  • Financial Risk/Toxicity
Decision to start treatment or not?

• Patient’s desire vs. Family’s desire
• Futile or not
• Women vs. Men
• Moms vs. Everyone Else
• Zita’s Plan
Decision to stop treatment

• Revisit the Plan of Care
• Treatment is futile or more toxic than the disease
• Emotional desire to continue vs. physical ability
• Are we stopping or taking a break?
• The decision to stop treating the cancer is not a decision to stop treating the patient.
• It is essential to reassure the patient and family that you are not abandoning them!!
Decision to withhold or stop treatment

• Easy
  • Patient, family and physician agree

• Difficult
  • Patient and physician agree, while family disagrees

• Near impossible
  • Patient is mentally competent but refuses or won’t decide
  • Patient is not competent, but family, DPOA refuses or won’t decide
  • Everyone but the physician refuses to stop because it is God’s hands to decide.
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• Patient and family agree that further therapy is futile and agree to palliative care

Autonomy? Beneficence/Non-maleficence? Justice?
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Conclusions

• Develop a Plan of Care
• Periodically ask the patient to explain to you why she is taking treatment.
• In front of family members, ask the patient if the treatment is going the way she expected it to.
• Convey the intent to treat the patient regardless of how treatment of the disease is going.
• Encourage assignment of DPOA
• Encourage palliative care sooner rather than later.
When all is said and done, it’s not that complicated. What she told you was true.

“Respect others, and do good.”

Your Mom
“Live long, live well, die fast.”

Could be a Korean proverb.

Sechin Cho, MD